National Digestive Diseases Information Clearinghouse

NDDIC News

SPRING 2004

National Institute of Diabetes and Digestive and Kidney Diseases

NATIONAL INSTITUTES OF HEALTH

New NIDDK Branch Focuses on Liver Disease

A new Liver Disease Research Branch at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) will focus research efforts on the critical areas of hepatitis B and C, clinical liver disease, liver and biliary diseases, and liver transplantation.

Heading the new branch is Dr. Jay H. Hoofnagle, former director of NIDDK's Division of Digestive Diseases and Nutrition (DDN) and one of the world's leading authorities in the field of liver disease.

"This is not just a shuffling of the deck chairs," says Dr. Hoofnagle, noting that the new branch is the result of "strong interest" from Congress and the lay community in raising the status of liver disease within the Institute. The new branch will function within the DDN division, but with its own branch chief, staff, and an exclusive focus on the liver and liver disease. "This will give liver research its own home at the NIH," Dr. Hoofnagle says. Dr. Stephen James, former deputy director of DDN, is now the division's director.

Dr. Jay H. Hoofnagle heads NIDDK's new Liver Disease Research Branch.

Thirty years ago, 75 percent of chronic liver disease was believed due to alcohol and 99 percent was considered untreatable. "We now know that alcohol actually represents a minority of cases—about 20 percent—and there are many forms of the disease that are now treatable or preventable," says Dr. Hoofnagle, whose own research at NIH with interferon during the 1980s resulted in the first cures of hepatitis C–infected individuals. "We still see the original patients from those studies, and they haven't had any evidence of residual liver disease or the virus," he notes.

LIVER DISEASE, *continued on page 4*

Inside This Issue...

U.S. Department of Health and Human Services

Interagency Committees Review Progress in Understanding IBD, PBC; Establish New Research Priorities

The Division of Digestive Diseases and Nutrition (DDN), part of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), manages research programs addressing a wide range of digestive diseases. In addition to evaluating and funding digestive research through grants and clinical trials, DDN staff members work with representatives of other Federal agencies to coordinate all Government efforts in this area and to set research priorities.

In recent months, DDN personnel have led two interagency committees to review progress in inflammatory bowel disease and primary biliary cirrhosis. The June 2003 meeting on PBC was the first of the newly convened Liver Diseases Interagency Coordinating Committee.

Inflammatory Bowel Disease (IBD)

In April 2003, the Digestive Diseases Interagency Coordinating Committee (DDICC) met to review the current state of research on IBD and recommend appropriate directions for new research. Guest speakers included leading researchers, clinicians, academicians, and policymakers in the field of gastroenterology.

Dr. Richard Blumberg of Harvard Medical School reviewed the strategic plan of the Crohn's and Colitis Foundation of America (CCFA). He identified a number of promising areas of research that CCFA is supporting, including genetic and molecular studies and epidemiological studies to identify novel risk factors, and endorsed randomized clinical trials in important human disease models (e.g., postsurgical relapse or pouchitis) and the coupling of these trials with translational studies.

Dr. Charles O. Elson of the University of Alabama at Birmingham reviewed the immunology and microbiology of IBD. He emphasized that researchers need to delineate the function of the genes associated with it and reach a fuller understanding of the relationship of these genes to the microbiota, the epithelium, and the immune system. Recently developed technologies, such as genetically defined microbes, epithelial cell studies, induced mutant mice models, gnotobiotic facilities, and gene expression arrays, enable investigators to examine the mechanism and manipulation of gene interaction and its implications for IBD research.

In talking about the genetics of IBD, Dr. John Rioux of the Whitehead Institute in Cambridge (MA) listed priority areas for future research: identifying IBD genes and causal genetic variation in understudied populations, understanding the role of IBD genes in biology and pathophysiology, and determining the influence of genetic variation on disease.

Dr. Daniel Podolsky of Massachusetts General Hospital in Boston spoke about the epithelial biology of IBD. He stated that a central research objective over the next few years will be to understand more completely how the proteins that form the tight-junction structure of the epithelium are dynamically regulated to sustain the digestive system's barrier and how the epithelial monolayer can be repaired after ulceration has occurred. Dr. Podolsky concluded that understanding the alterations in the epithelial compartment that are associated with or contributing to IBD would enable researchers to design more effective therapies.

Dr. Robert Sandler of the University of North Carolina spoke about the epidemiology of IBD. He pointed out that it is more prevalent in the northern regions of the world and that when individuals move from areas of low incidence to areas of high incidence, their susceptibility increases. These findings indicate that IBD has an environmental as well as a genetic component. According to Dr. Sandler, the best estimates indicate that 1 million people in the United States have IBD. However, even those estimates, based on the only population studies to date, came from an area

INTERAGENCY COMMITTEES, *continued on page 6*

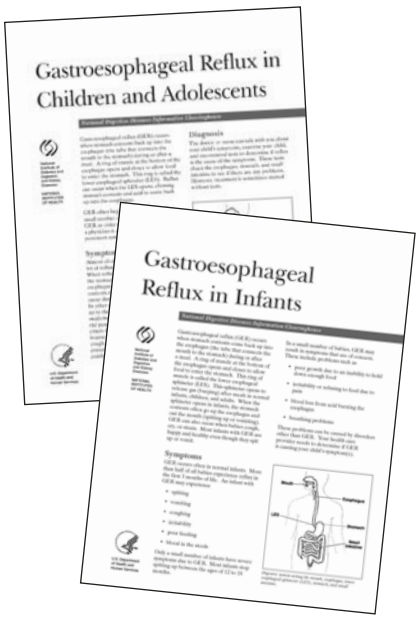
New National Education Campaign on Pediatric Gastroesophageal Reflux Disease

The Children's Digestive Health and Nutrition Foundation (CDHNF) partnered with the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) to launch an awareness campaign in pediatric gastroesophageal reflux disease (GERD). Aimed at physicians and the general public, the Pediatric GERD Education Campaign seeks to improve the awareness, understanding, diagnosis, and treatment of GERD in infants, children, and adolescents. GERD occurs when the contents of the stomach back up into the esophagus. This common disease is sometimes overlooked in infants and children, and it can lead to more serious health problems in adults. The campaign aims to increase the detection and treatment of GERD in children and adolescents.

The campaign is chaired by Harland S. Winter, M.D., and features

- A comprehensive lecture kit based on the *NASPGHAN Guidelines on Pediatric GERD.* The materials, on CD–ROM, include slides and commentaries, references, and handouts. The presentation can be tailored to the audience. In addition, attendees are eligible for continuing medical education (CME) credits; CME forms are included on the CD–ROM.
- Grand Rounds presentations on GERD. Volunteer NASPGHAN members have led sessions across the country. Innovative teaching tools developed especially for the campaign will ensure that speakers give interesting and informative presentations.
- Materials for primary care physicians and their patients about the *NASPGHAN Guidelines on Pediatric GERD.* Key points are presented in new easy-to-understand formats. The materials will be distributed at Grand Rounds, by direct mail, and at professional meetings.
- Two new websites about pediatric GERD:
  - *www.kidsacidreflux.org* for parents and young children
  - *www.teensacidreflux.org* for adolescents
- Two new fact sheets from NASPGHAN and NDDIC for physicians and their patients: *Gastroesophageal Reflux in Infants* and *Gastroesophageal Reflux in Children and Adolescents*

All materials were developed in conjunction with a 14-member scientific advisory board. For more information about the campaign or to request printed materials, call 1–800–344–8888. Campaign materials are also available online at *www.cdhnf.org* or *www.naspghan.org.* To request copies of the *Gastroesophageal Reflux in Infants* and *Gastroesophageal Reflux in Children and Adolescents* fact sheets, contact NDDIC at 1–800–891–5389 or see them online at *www.digestive.niddk.nih.gov.* ■



Liver Disease, *continued from page 1*

While the incidence of alcoholic liver disease is declining, hepatitis C–related liver disease is up, due to increased use of injection drugs and multiple sexual partners. "The lifestyle that came in the 1960s was bad on the liver," says Dr. Hoofnagle.

With more than 3 million Americans infected with the virus, one-third of whom will develop cirrhosis, many eventually requiring liver transplantation, hepatitis C will be a primary focus of the new branch, which will fund extramural efforts at research centers across the country. Optimal treatment with new, long-acting pegylated interferon (PEG interferon alfa) and the antiviral drug ribavirin has resulted in eradication of the virus in 50 percent of patients, according to Dr. Hoofnagle. "Hepatitis C is the big issue," he says. "There's marvelous research going on—better understanding of the virus, new insights into how it harms the liver, and recently, better antivirals, protease inhibitors, helicase inhibitors, and cytokines, like interferon. There's a light at the end of this tunnel."

Hepatitis B is also coming under control, he says. There are currently three licensed treatments—interferon, lamivudine (Epivir), and adefovir (Hepsera). "There are also a handful of drugs pending and combination therapy being tested," says Hoofnagle. "I think hepatitis B will be a fully treatable disease in the next 5 to 10 years."

NASH, or nonalcoholic steatohepatitis, a newly identified liver disease common among obese individuals and people with diabetes, is high on the new branch's targeted list. Studies to find the cause, natural history, and treatment of NASH are under way. "Five years ago, we didn't have a single grant for NASH," Dr. Hoofnagle says. NASH seems to be caused by obesity and insulin resistance. Treatments, he says, will likely include weight loss, physical activity, antioxidants, and antidiabetes drugs.

Autoimmune liver diseases, like autoimmune hepatitis, primary biliary cirrhosis, and sclerosing cholangitis, "are tough," according to Dr. Hoofnagle. "We don't know what causes them, and treatments improve but do not cure them."

Autoimmune hepatitis is treated with steroids, while primary biliary cirrhosis, which affects 1 in 2,000 women and eventually leads to liver transplantation, can be slowed down by a drug called ursodiol (Actigall). "We have to get at the cause of this disease, prevent, and actually cure it," says Hoofnagle.

One in 5,000 children born each year has biliary atresia—lacking bile ducts—and most of these children will eventually need a liver transplant. The supply of donor livers for these children—as well as for adults with cirrhosis or liver cancer and for others approaching liver failure—will be a big issue for the new branch.

The branch will be directly responsible for liver research funding by NIDDK but will also have the charge to collaborate with and promote liver research in other Institutes involved in such work. Efforts in other Institutes include the study of liver cancer at the National Cancer Institute, viral hepatitis at the National Institute of Allergy and Infectious Diseases and the National Institute on Drug Abuse, biliary atresia at the National Institute of Child Health and Human Development, alcoholic hepatitis at the National Institute on Alcohol Abuse and Alcoholism, and imaging of the liver at the National Institute of Biomedical Imaging and Bioengineering.

Liver transplantation is extremely successful; long-term survival is possible and some patients are able to stop all their immunosuppressive medications. However, there are not enough livers available for all the people who need them. "Several thousand people die on the transplant list a year," says Dr. Hoofnagle. "We need to find more donors and other sources of livers."

The solutions to these pressing clinical issues are most likely to come from basic liver research, including studies of how the liver is formed, how stem cells differentiate into adult liver cells, how the liver functions, how to overcome liver transplantation rejection, and how to engineer artificial livers or how to prepare animal livers that can be used in humans (xenotransplantation), says Dr. Hoofnagle. ■

Dr. James Is Named Director of DDN

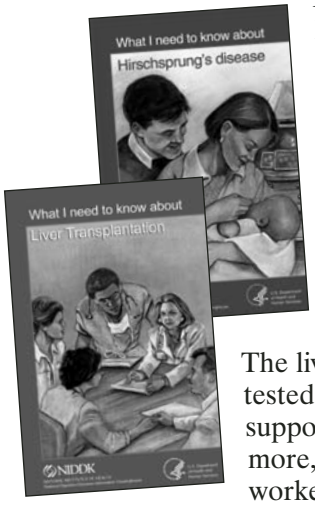
Stephen P. James, M.D., was recently appointed to direct the Division of Digestive Diseases and Nutrition (DDN) within the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

Dr. James directed the division of gastroenterology at the University of Maryland's School of Medicine for 10 years before joining NIDDK in February 2001. His extensive experience in gastroenterology and hepatology as well as proven leadership and management abilities will serve the NIDDK and the NIH well. In his role as director of DDN, he will be in charge of planning, conducting, and evaluating a national research effort focused in the areas of gastrointestinal, pancreatic, hepatobiliary, and nutrition diseases and conditions.

The clearinghouse congratulates Dr. James on his appointment. ■

NDDIC Wins NIH Plain Language Awards and World Wide Web Health Information Award

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Information Clearinghouses received 12 NIH Plain Language awards in 2003 and 2004, including Outstanding awards for the National Digestive Diseases Information Clearinghouse's (NDDIC's) *What I need to know about Hirschsprung's Disease* in 2003 and *What I need to know about Liver Transplantation* in 2004. These awards were established to promote the National Institutes of Health (NIH) Plain Language Initiative, established in response to a 1998 White House memorandum calling for all Federal Government writing to be in plain language.



The liver transplantation booklet was field-tested by 16 members of liver transplantation support groups in Northern Virginia and Baltimore, MD. The field-testers consisted of social workers, patients who have either received or are awaiting a transplant, and family members of patients.

NIDDK staff attended the awards ceremony on April 20, 2004, at the NIH's Lipsett Auditorium. Joe Palca of NPR, the keynote speaker, discussed how articles written without unnecessary words are clear and easy to understand.

The Hirschsprung's disease booklet was field-tested online with members of the Guardian Society, a support group for parents whose children have Hirschsprung's disease, and in person with nurse practitioners at the National Conference for Nurse Practitioners held in 2000 in Washington, DC.

In addition, the clearinghouses received nine Honorable Mention awards, including three for NDDIC:

- *What I need to know about Irritable Bowel Syndrome*
- *What I need to know about Colon Polyps*
- *What I need to know about Peptic Ulcers*

NDDIC staff attended the awards ceremony on April 23, 2003, at the NIH's Lipsett Auditorium. Cokie Roberts, the keynote speaker, described how materials that were written in plain language helped her tremendously in her battle with cancer. Ms. Roberts has been a patient at NIH and praises it for its efforts in supporting this initiative.

In addition, the recently revamped NDDIC website won a Bronze award at the World Wide Web Health Information Awards. The NIDDK online catalog also won a Bronze award. ■

INTERAGENCY COMMITTEES, *continued from page 2*

where IBD rates are suspected to be higher than in most other regions in the country.

Dr. Bruce E. Sands of Massachusetts General Hospital discussed clinical research. He said that identifying surrogate markers is the main goal of current IBD researchers because endoscopies are invasive, expensive, and often imperfect. Dr. Sands stressed that the need for patient-oriented investigators in IBD has reached the crisis point and that, unless this problem is corrected, many questions will go unanswered.

Dr. Warren Strober of the National Institute of Allergy and Infectious Diseases (NIAID) described intramural research at the National Institutes of Health. NIAID's Mucosal Immunity Section (MIS) is studying murine models of mucosal inflammation, such as TNBS-colitis—colitis induced by the introduction of tri-nitrobenzene sulfonic acid into the rectums of mice. Using this model, the MIS has shown that Th-1 colitis is treatable with anti-interleukin (IL)-12. He also described a number of human studies, including studies of the clinical effectiveness and immunological impact of anti-IL-13 therapy, and emphasized the importance of collaborative programs. For example, a consortium organized to study anti-IL-13 therapy or interferon beta therapy could help find a new therapy for ulcerative colitis.

Dr. Frank Hamilton of DDN outlined the success of NIDDK's IBD funding, which has increased from $8.9 million in fiscal year 1992 to over $36 million in fiscal year 2002. Currently, NIDDK-supported IBD research includes the three Digestive Disease Centers, which have four projects representing approximately 20 percent of the product portfolio. In addition, the Institute funds 121 R01 and R03 IBD research grants, among them a multicenter trial on IBD; Career Development awards, which have bolstered the program and contributed to the development of new investigators; and the Small Business Innovation Research program, which has received renewed emphasis.

Dr. Stephen James of NIDDK, DDICC executive secretary, asked Dr. Robert Karp, head of NIDDK's genetics of digestive diseases program, to discuss the IBD Genetics Consortium. Dr. Karp then described the consortium, which is composed of six research centers and one data coordinating center and has annual funding of $2 million. It is primarily trying to identify susceptibility genes for IBD. To that end, it is creating a patient repository, immortalized cell lines, and DNA samples and will ultimately form an extensive database for analysis.

Dr. James thanked the participants for their input and stated that maintaining a continuous dialog between meetings is imperative.

Congress has charged DDICC with coordinating research activities between various institutes and agencies within the Federal Government. The committee, led by NIDDK, includes representatives from the Center for Scientific Review; Food and Drug Administration; Health Resources and Services Administration; National Heart, Lung, and Blood Institute; National Institute of Nursing Research; and National Institute on Alcohol Abuse and Alcoholism.

Primary Biliary Cirrhosis (PBC)

In June 2003, Dr. Jay Hoofnagle, director of NIDDK's new Liver Disease Research Branch, chaired the first meeting of the Liver Disease Interagency Coordinating Committee. The topic under review was translational research in PBC.

After Dr. Hoofnagle's opening remarks on the challenges of translational research, Dr. M. Eric Gershwin of the University of California at Davis reviewed what is known about the pathogenic role of autoreactive B and T cells and outlined questions about the mechanism that turns the immune system against biliary epithelial cells and destroys bile ducts. Dr. Keith D. Lindor of the Mayo Clinic then moderated a discussion on this topic.

INTERAGENCY COMMITTEES, *continued on page 7*

Take In NIH Conferences Without Leaving Your Desk

Can't fly to the NIH campus to attend a conference or workshop that looks particularly interesting? You can still get all the information you need by logging on to *www.videocast.nih.gov.* A complete schedule of current and future events, plus an archive of past events, is available on this website. Most of the conferences are available to anyone who accesses the website.

A few of the available presentations that may be of interest to readers of *NDDIC News* are

- **Demystifying Medicine—Inflammatory Bowel Disease: Mechanisms**
  Tuesday, April 6, 2004
- **Is It Ethical to Conduct Research With Individuals Who Have No Access to Standard Treatment?**
  Wednesday, April 7, 2004
- **Women's Health Scientific Group**
  Friday, April 9, 2004
- **Demystifying Medicine—Iron and Disease—Hemochromatosis—Metabolism Regulation**
  Tuesday, April 13, 2004

The Center for Information Technology (CIT) makes special NIH events, seminars, and lectures available to viewers on the NIH network and the Internet from the VideoCast website. VideoCasting electronically streams digitally encoded video and audio data from a server to a client. Streaming video is best viewed with a high-speed network connection and high-color or better color setting. At a minimum, your computer will need VGA graphics with at least 256 colors, a sound card with speakers or headphones, and a network connection or high-speed modem. VideoCasts can be viewed using RealOne or RealPlayer software, which can be downloaded and installed for free from *Real Networks.* (http://www.real.com/) ■

INTERAGENCY COMMITTEES, *continued from page 6*

Dr. Burton Combes of the University of Texas Southwestern at Dallas reported on a multicenter trial of methotrexate therapy for PBC. The randomized, double-blind trial, designed to compare the efficacy of ursodiol plus methotrexate versus placebo, was terminated early because of the lack of any evidence that methotrexate benefited patients with PBC. Ursodiol plus methotrexate was no more effective than ursodiol alone, and methotrexate can have serious side effects.

Dr. Lindor discussed newer therapies for PBC, including modulation of the body's immune response to pyruvate dehydrogenase, lamivudine, tetracycline, bezafibrate, silymarin (milk thistle), budesonide, and mycophenolate mofetil plus ursodeoxycholic acid (UDCA). Dr. Lindor reported that lamivudine, bezafibrate, and mycophenolate mofetil appear to be the most promising therapies at the moment.

Dr. Henry C. Bodenheimer Jr. of Beth Israel Medical Center in New York City then moderated a discussion on the two preceding presentations.

Finally, Dr. Jeffrey N. Siegel of the Food and Drug Administration spoke about anticytokine therapy in autoimmune disease. Researchers have observed that cytokines play a part in all autoimmune diseases by controlling the mechanisms for inflammation and tissue repair. Agents that block cytokine action show promise in treating several autoimmune diseases. Further testing will be required to determine the long-term effect of these drugs and assess cost-benefit factors.

The meeting closed with a discussion of future research priorities moderated by Dr. Hoofnagle. ■

Upcoming Conference

NIH Consensus Development Conference on Celiac Disease

June 28–30, 2004

Recent studies, primarily in Europe but also in the United States, suggest that the prevalence of celiac disease is much higher than previous estimates, raising the concern that the disease is widely under-recognized. Recent progress in identification of autoantigens in celiac disease have led to the development of new serological diagnostic tests, but the appropriate use of testing strategies has not been well defined. NIDDK and the Office of Medical Applications of Research (OMAR) of the National Institutes of Health (NIH) are sponsoring a consensus development conference to explore and assess the current scientific knowledge regarding celiac disease. The conference will address questions about testing and diagnosis, prevalence, manifestations and long-term consequences, management, and recommendations for future research on celiac disease and related conditions. ■

Recent NIDDK Conferences and Workshops

Phenotyping Obesity for Human Genetic Studies

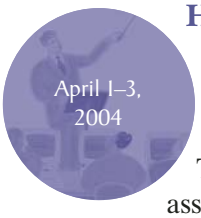
October 28–30, 2003

The genetics of human obesity has been very intensively studied, with at least 10 genome scans already published. These scans have yielded a large number of suggestive genetic linkage findings. However, these studies have yet to result in the identification of many of the genes predisposing to obesity. Identification of these genes has proven difficult, as in the case of so many genetically complex diseases, because many genes, each individually contributing a small effect, influence predisposition to obesity, and because different genes may predispose to obesity in different individuals, even though these individuals may appear to have very similar phenotypes. During this workshop, a wide range of anatomical, physiological, behavioral, and developmental phenotypes relevant to obesity and its major medical consequences were considered. Experts in metabolism, imaging, endocrinology, and genetics recommended reliable, cost-effective, high-throughput methods for measuring morphological, physiological, behavioral, and developmental phenotypes associated with obesity that would be practical to implement in a large-scale human genetic study of 2,000 to 5,000 subjects.

Physiological Mechanisms Linking Obesity and Its Comorbidities

December 11–13, 2003

This conference investigated the mechanisms leading to the altered physiology and metabolism observed in obesity, particularly those that often lead to other comorbidities. For example, inflammatory response appears to be involved in cardiovascular disease, diabetes, asthma, nonalcoholic fatty liver disease, and osteoarthritis. Refining current classifications of fat mass as a better predictor of disease risks was considered. New knowledge will lead to new treatment and prevention paradigms. Such knowledge may serve to provide intermediate markers for intervention outcomes and an improved phenotypic characterization and identification of obesity over the currently used body mass index.



Hepatocellular Carcinoma: Screening, Diagnosis, and Management

April 1–3, 2004

The goals of this meeting are to assess the current status of hepatocellular carcinoma (HCC) in the United States, focusing on its prevalence and incidence, methods

RECENT CONFERENCES, *continued on page 13*

What's New From NDDIC?

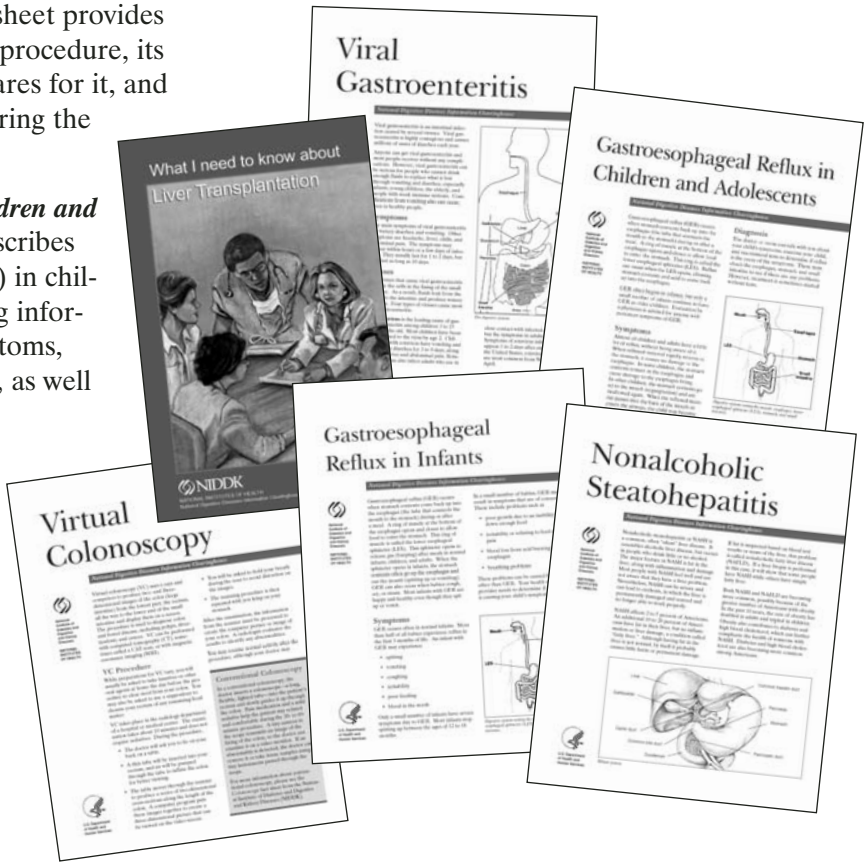
The National Digestive Diseases Information Clearinghouse (NDDIC) is pleased to announce several new and updated publications. All NDDIC materials are available online at *www.digestive.niddk.nih.gov.*

New Materials

- ***Viral Gastroenteritis.*** This fact sheet provides information about the symptoms, causes, transmission, diagnosis, and treatment of viral gastroenteritis to patients, family, and friends, as well as to doctors and other health care professionals.
- ***What I need to know about Liver Transplantation.*** This booklet provides comprehensive information in a generously illustrated, easy-to-read format for people who are facing the possibility of liver transplantation. It includes information about liver function, contraindications to surgery, symptoms of liver problems, organ donation and distribution, conditions leading to transplantation, and follow-up care after surgery.
- ***Virtual Colonoscopy.*** This fact sheet provides general information about the procedure, its purpose, how the patient prepares for it, and what the patient can expect during the procedure and afterward.
- ***Gastroesophageal Reflux in Children and Adolescents.*** This fact sheet describes gastroesophageal reflux (GER) in children and adolescents, including information about the causes, symptoms, and diagnosis of this condition, as well as its treatment.
- ***Gastroesophageal Reflux in Infants.*** This fact sheet describes gastroesophageal reflux (GER) in infants, including information about the causes, symptoms, and diagnosis of this condition, as well as its treatment.
- ***Nonalcoholic Steatohepatitis.*** This fact sheet provides information about NASH, a liver disease that occurs when fat deposits in the liver cause inflammation. It describes underlying conditions or risk factors, symptoms, causes, diagnosis, treatment, and ongoing research.

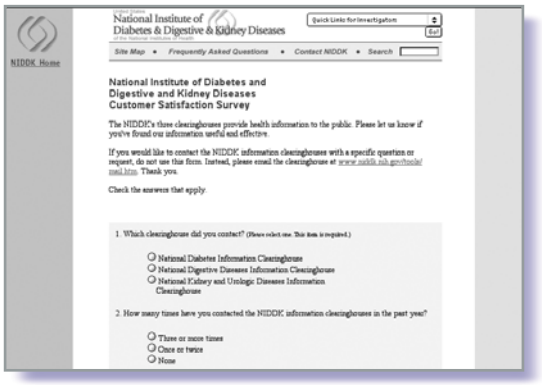
Updated Publications

- ***Lactose Intolerance***
- ***Chronic Hepatitis C: Current Disease Management***
- ***Irritable Bowel Syndrome***
- ***Constipation***
- ***What I need to know about Constipation*** (formerly titled ***Why Am I Constipated?***) ■



Customer Satisfaction Survey

The customer satisfaction survey, launched by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) information clearinghouses in 2001, has been extremely helpful in providing the National Digestive Diseases Information Clearinghouse (NDDIC) with customer feedback. The survey results have helped clearinghouse staff identify customers' needs and provide additional services in response to those needs.



The survey is available on the NIDDK website, via clearinghouse email responses, and in print format—one survey is included with every publication order. NDDIC information specialists also conduct surveys over the telephone. The replies to the survey are entered into a database, where the data are compiled.

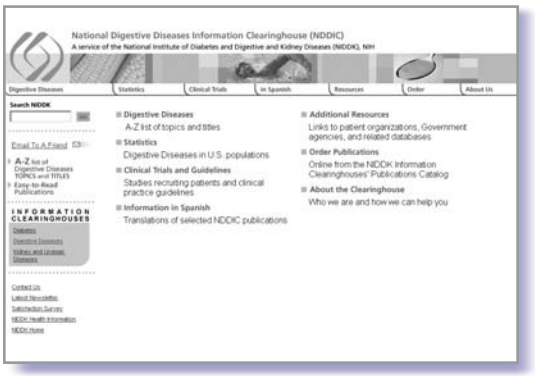
Survey results from the past 12 months indicate that the Internet and NIDDK publications are the two main referral sources for NDDIC. Clearinghouse responsiveness, or the quickness and efficiency with which NDDIC responds to inquiries, is also rated by customers who complete the survey. Nearly 93 percent of survey respondents rate clearinghouse responsiveness as excellent or good.

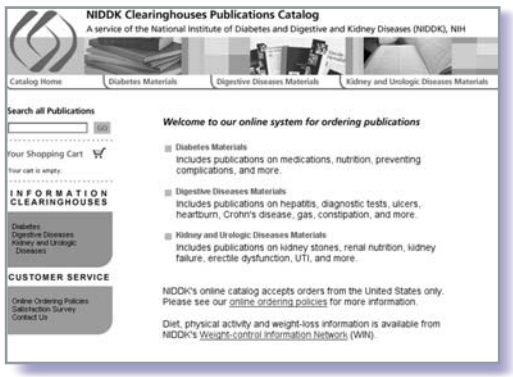
NDDIC has also received many compliments through the survey, including thanks for quick responses and helpful information.

In response to suggestions received through the survey, the clearinghouse developed and launched an online ordering system (see below for additional information) and will continue to promote clearinghouse services. NDDIC staff look forward to receiving customer feedback and providing additional services. ■

What You Need to Know About NDDIC Online

The National Digestive Diseases Information Clearinghouse (NDDIC) has a new look and a new way to order publications. You can see our new colors, design, and navigation features at our new streamlined address: *www.digestive.niddk.nih.gov.*

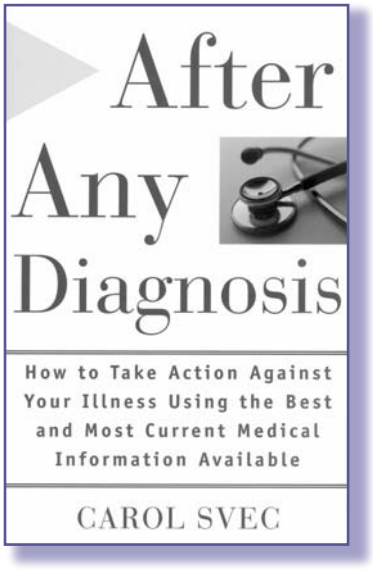




Many customers of NDDIC have asked to order publications online and to use credit cards to pay for bulk orders. Now they can. The NIDDK has also launched the NIDDK publications catalog website at *www.catalog.niddk.nih.gov,* where folks can fill their shopping carts with free single copies or low-cost bulk orders for their practices and clinics and pay with plastic. ■

NDDIC Coordinating Panel Meeting Focuses on Internet Health Information

At the National Digestive Diseases Information Clearinghouse's (NDDIC's) annual Coordinating Panel meeting in June 2003, participants heard from guest speaker Carol Svec, author of *After Any Diagnosis: How to Take Action Against Your Illness Using the Best and Most Current Medical Information Available.* Ms. Svec discussed the Internet, an evolving resource that plays an increasingly significant role in the lives of patients seeking to understand their illnesses, and explained what many consumers are looking for online. She also offered advice to panel members on how to create effective websites for consumers.



NDDIC Director Kathy Kranzfelder updated participants on clearinghouse activities over the past year. Five new publications were developed: fact sheets on *Barrett's Esophagus* and *Viral Gastroenteritis* and easy-to-read booklets about peptic ulcers, colon polyps, and liver transplantation. She noted that the clearinghouse responded to more than 10,000 inquiries and that the number of email inquiries has more than tripled over the past year, bringing the total to 4,950. These figures underscore the Internet's importance in reaching consumers.

Dr. Stephen James updated panel members on activities of the Division of Digestive Diseases and Nutrition (DDN) at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), beginning with the newly established Liver Disease Research Branch, directed by Dr. Jay Hoofnagle. Dr. James discussed current initiatives for research funding, which include the following:

- HALT–C—a long-term study on hepatitis C
- Virahep-C—a clinical trial of peginterferon and ribavirin combination therapy
- Recurrent hepatitis B after liver transplantation
- Long-term followup of the NIDDK Liver Transplantation Database
- Nonalcoholic Steatohepatitis (NASH) Clinical Research Network
- Biliary Atresia Clinical Research Network
- Adult-to-adult living donor liver transplant
- LOOK AHEAD (Action for Health in Diabetes)
- CORI
- Genome anatomy projects
- IBD Genetics Consortium

Panel Meeting, *continued on page 16*

What's New in CHID?

CHID online

The Combined Health Information Database (CHID) is produced by health-related agencies of the Federal Government. This database provides the titles, abstracts, and availability of health information and health education resources. NDDIC maintains the digestive diseases section of the database, which includes information about books, pamphlets, videos, journal articles, and manuals on a variety of digestive disease topics. NDDIC continually adds new materials to CHID; following are brief examples of recent additions. To search CHID for materials on specific topics, go to *http://chid.nih.gov* on the Internet.

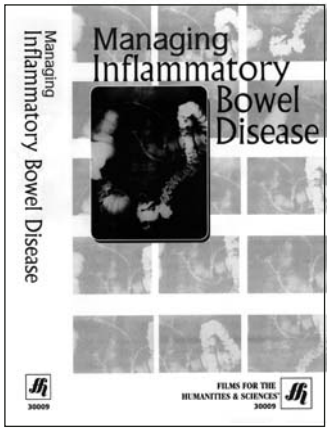
American Gastroenterological Association Nighttime Heartburn Relief Effort

Heartburn, or acid indigestion, is an all-too-common experience for many Americans. The burning sensation or pain in the chest from heartburn can extend from the breastbone and move upward to the neck and throat, often leaving a bitter or acid taste. This fact sheet describes an educational program from the American Gastroenterological Association (AGA) called the Nighttime Heartburn Relief Effort. This program is designed to help professionals and patients understand the symptoms of nighttime heartburn and the importance of having any chronic symptoms diagnosed and treated. Using a number of communications vehicles including direct-to-consumer, Internet, and third-party components, the campaign reached health care professionals as well as consumer audiences with key messages about diagnosis and treatment of nighttime heartburn. The fact sheet lists the campaign's objectives, completed projects and available materials, and upcoming projects.

Available from American Gastroenterological Association, 4930 Del Ray Avenue, Bethesda, MD 20814. (301) 654–2055. Fax: (301) 654–5920. Email: *info@gastro.org.* Website: *www.gastro.org.* Price: Contact organization for print copies.

Managing Inflammatory Bowel Disease

For reasons that are not altogether certain, inflammatory bowel disease (IBD) is affecting more and more Americans every year. In this videotape program from The Doctor Is In, Dr. Scott Plevy, formerly of Mount Sinai School of Medicine, and Dr. Susan Edwards, of the Dartmouth-Hitchcock Medical Center, seek to understand the spreading incidence of IBD. The doctors consider both Crohn's disease and colitis, the two primary forms of IBD, while describing pharmaceutical and surgical treatment options. The program includes case studies of two young women with IBD that focus on how they manage their debilitating conditions.



Available from Films for the Humanities and Sciences, PO Box 2053, Princeton, NJ 08543–2053. 1–800–257–5126. Fax: (609) 275–3767. Website: *www.films.com.* Price: $129.95 for VHS; $154.95 for DVD, plus shipping and handling. Item number: BVL3009.

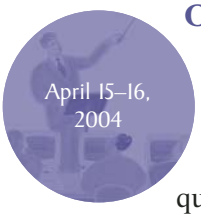
Biliary Atresia

This brochure describes biliary atresia, a condition in infants in which the bile duct outside the liver that carries bile from the liver to the small intestine is damaged. This prevents bile from leaving the liver so it accumulates and causes progressive damage to the liver tissue. In addition, there is ongoing damage to smaller bile ducts inside the liver. Unless bile flow can be established, liver function is gradually lost and affected children rarely survive beyond 2 years. The brochure describes the role of bile, the causes of the disease, the typical symptoms, treatment strategies (surgery called the Kasai procedure is usually the first option), secondary treatment options, complications of the disease, and the indications for liver transplantation in children with biliary atresia. The brochure concludes with the contact information of the Canadian Liver Foundation (*www.liver.ca*).

Available from Canadian Liver Foundation, Suite 1500, 2235 Sheppard Avenue East, Toronto, Ontario, Canada M2J 5B5.
(416) 491–3353 or 1–800–563–5483.
Fax: (416) 491–4952.
Email: *clf@liver.ca.*
Website: http://liver.ca.
Price: Contact organization for print copies. ■

Recent Conferences, *continued from page 8*

for screening, means of diagnosis and staging, and management, including the use of liver transplantation. The meeting will be jointly sponsored by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the National Cancer Institute (NCI), the National Institute of Bioengineering, Imaging, and Biotechnology (NIBIB), and the Department of Veterans Affairs (VA). The focus of the meeting will be to achieve agreement and develop recommendations based on current trends in the incidence of HCC; its epidemiology, high-risk groups, adequacy and effectiveness of screening in high risk populations, and means of early diagnosis; and optimal approaches to management and treatment including surgery, chemoembolization, radiofrequency ablation, and cadaveric and living donor liver transplantation. Another important aim of the meeting is to delineate the specific needs for future basic and clinical research on HCC. A summary of the meeting and its conclusions and recommendations will be submitted for publication. The speakers will be asked to give unbiased and scholarly overviews of the issues to support evidence-based recommendations.



Organ Innervation: Development, Disease, and Repair

April 15–16, 2004

Organ dysfunction as a consequence of neural defects or injury is a common and debilitating problem. The purpose of this workshop is to focus attention on organ innervation so that impediments to research in this area can be identified. An international group of investigators will convene to discuss innervation during development and disease progression and following injury. Developmental mechanisms underlying neural crest fate specification and migration to specific organs as well as factors that guide these processes and regulate neural survival will be considered. Mechanisms of neural injury, autonomic plasticity, and repair will also be emphasized. The workshop is intended to stimulate collaboration between investigators approaching the topic of organ innervation from developmental, disease, and repair perspectives. The workshop will also include a brainstorming session regarding areas of future scientific opportunity.

For additional information on these and other conferences and workshops, please visit *www.niddk.nih.gov/fund/other/conferences.htm.* ■

NDDIC Publications List

Patient Education Fact Sheets

Single copies free. Packages of 25, $5 each.

DD–196 Autoimmune Hepatitis
DD–193 Bacteria and Foodborne Illness
DD–202 Barrett's Esophagus
DD–29 Bleeding in the Digestive Tract
DD–179 Celiac Disease
DD–172 Chronic Hepatitis C: Current Disease Management
DD–73 Cirrhosis of the Liver
DD–35 Constipation
DD–117 Crohn's Disease
DD–195 Cyclic Vomiting Syndrome
DD–185 Diarrhea
DD–27 Diverticulosis and Diverticulitis
DD–02 Facts & Fallacies About Digestive Diseases
DD–197 Fecal Incontinence
DD–97 Gallstones
DD–30 Gas in the Digestive Tract
DD–208 Gastroesophageal Reflux in Children and Adolescents
DD–209 Gastroesophageal Reflux in Infants
DD–186 Gastroparesis and Diabetes
DD–177 *H. pylori* and Peptic Ulcer
DD–160 Heartburn, Hiatal Hernia, and Gastroesophageal Reflux Disease (GERD)
DD–191 Hemochromatosis
DD–59 Hemorrhoids
DD–14 Irritable Bowel Syndrome
DD–48 Lactose Intolerance
DD–212 Nonalcoholic Steatohepatitis
DD–71 Pancreatitis
DD–52 Smoking and Your Digestive System
DD–15 Ulcerative Colitis
DD–178 Vaccination for Hepatitis A and B
DD–206 Viral Gastroenteritis
DD–192 Viral Hepatitis A to E and Beyond
DD–207 Virtual Colonoscopy
DD–03 Your Digestive System and How It Works

Diagnostic Tests Folder

First folder free. Packages of 25 folders, $10 each.

DD–180 Diagnostic Tests Folder

Patient Education Booklets (Easy-to-Read)

Single copies free. Packages of 25, $10 each.

DD–167 The Digestive Diseases Dictionary

What I need to know about

DD–203 Colon Polyps
DD–168 Constipation
DD–169 Gas
DD–174 Hepatitis A
DD–175 Hepatitis B
DD–176 Hepatitis C
DD–198 Hirschsprung's Disease
DD–194 Irritable Bowel Syndrome
DD–205 Liver Transplantation
DD–204 Peptic Ulcers
DD–181 Why Does Milk Bother Me?

Spanish Materials

Single copies free. Packages of 25, $10 each unless otherwise stated.

DD–200 Cirrhosis of the Liver (Packages of 25, $5 each.)
DD–182 *H. pylori* and Peptic Ulcer (Packages of 25, $5 each.)

What I need to know about

DD–199 Constipation
DD–211 Gas
DD–187 Hepatitis A
DD–188 Hepatitis B
DD–189 Hepatitis C
DD–201 Your Digestive System and How It Works (Packages of 25, $5 each.)

Statistics

DDI–27 Digestive Disease Statistics. (Single printed copies free to those without Internet access.)
DD–159 Digestive Diseases in the United States: Epidemiology and Impact ($15 each)

Information Packets

Single copies free. No bulk orders.

DD–137 Anal Fissure
DD–133 Diagnostic Tests for Liver Disease
DD–152 Gallbladder and Biliary Tract Diseases

Online Publications

Single printed copies free to those without Internet access.

DDI–18 Appendicitis
DDI–28 Collagenous Colitis and Lymphocytic Colitis
DDI–19 Constipation in Children
DDI–26 Gastritis
DDI–24 Ileostomy, Colostomy, and Ileoanal Reservoir Surgery
DDI–21 Indigestion
DDI–14 Inguinal Hernia
DDI–01 Intestinal Pseudo-Obstruction
DDI–22 Irritable Bowel Syndrome in Children
DDI–08 Ménétrier's Disease
DDI–23 NSAIDs and Peptic Ulcers
DDI–09 Porphyria
DDI–03 Primary Biliary Cirrhosis
DDI–04 Primary Sclerosing Cholangitis
DDI–16 Proctitis
DDI–17 Rapid Gastric Emptying
DDI–05 Short Bowel Syndrome
DDI–11 Whipple's Disease
DDI–12 Wilson's Disease
DDI–13 Zollinger-Ellison Syndrome

Other Materials

Single copies free.

DD–05 Directory of Digestive Diseases Organizations for Patients
DD–06 Directory of Digestive Diseases Organizations for Professionals
DD–184CD Liver Transplantation Database CD ($20 each)
DD–22 National Digestive Diseases Information Clearinghouse brochure
DD–32 NDDIC News

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NIDDK–02 NIDDK Information Clearinghouses Publications Catalog

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Panel Meeting, *continued from page 11*

Current requests for applications for investigator-initiated research project grants include

- Bariatric surgery
- Hepatitis C
- Digestive diseases core centers
- Genetic modifiers of Mendelian diseases

Dr. Hoofnagle introduced panel members to the Liver Diseases Research Branch. Details of the new branch's missions and action plans can be found on page 1.

The final portion of the meeting consisted of reports about the organizations that make up the panel. Participants from the following organizations each took a few moments to tell the panel about their organization's activities over the past year.

- American College of Gastroenterology
- American Dietetic Association
- American Society for Gastrointestinal Endoscopy
- American Society of Colon and Rectal Surgeons
- Celiac Sprue Association/U.S.A., Inc.
- Crohn's and Colitis Foundation of America
- Celiac Disease Foundation
- Gluten Intolerance Group
- Hepatitis Foundation International
- International Foundation for Functional Gastrointestinal Disorders
- North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition
- Oley Foundation
- United Network for Organ Sharing
- United Ostomy Association

The NDDIC would like to thank each of these organizations for their continued input and insights. ■

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